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SOCIAL DISTANCE, STIGMA, AND HELP-SEEKING: AN EXPLORATION OF AUTISM
BELIEFS IN THE SOUTHERN U.S.

A Thesis
presented in partial fulfillment of requirements
for the degree of Master of Arts
in the Department of Psychology
The University of Mississippi

by

CHRISTIAN S. COURSON

May 2020

ABSTRACT

Stigma has been associated with physical and mental health conditions and their treatment long before formal care systems. Negative perceptions within the lay community, such as stigma and social distancing, negatively impact individuals with autism and their families. The purpose of this study was to explore factors associated with autism stigma among lay people in the Southern United States. Specifically, the study explored how demographics, knowledge, and familiarity are related to social distancing and stigma, and how these factors relate to beliefs about and intentions of help-seeking. Using a lay sample (N=108) of rural Southern towns, survey data was collected in two community settings (healthcare centers and churches). The survey consisted of questionnaires designed to measure an individual's knowledge of ASD, stigma, social distancing, and help-seeking attitudes. Multiple hierarchical regressions examined the following hypotheses: 1) demographics (i.e., age, gender, education level, and income level), ASD knowledge, and ASD familiarity will predict stigma 2) demographics, knowledge, and familiarity will predict social distancing 3) demographics, knowledge, familiarity, stigma, and social distancing will predict help-seeking intentions. Results partially supported the hypotheses. That is, individuals who have higher levels of ASD knowledge are less likely to hold stigmatized attitudes towards individuals with ASD. Individuals more familiar with someone with autism were less likely to prefer greater social distance. People who preferred higher amounts of social distance were more likely to avoid seeking help than individuals who had preference for less social distance. It appears that both are needed in order to reduce social distancing and increase help-seeking intentions. Taken together, these findings indicate an increased need for awareness

and intervention campaigns that provide psychoeducation along with opportunities for interaction. Contrary to previous literature, there were no indications that demographic variables (i.e., age, gender, educational level, or income level) significantly predicted any of these variables. Future research should focus on larger sample sizes with increased diversity in background and beliefs. Increased male representation would be helpful, as would efforts to study ASD phenomena in other regions of the United States and in the world.

Keywords: autism, ASD, stigma, help-seeking, social distancing

DEDICATION

This thesis is dedicated to my wife, Hannah Courson, and my mother, Mary Lynn Bailey, who both urged me through difficult times and loved me unconditionally.

ACKNOWLEDGMENTS

I express my deepest appreciation to my advisor, Dr. Laura Johnson, for urging me to pursue research about which I was passionate and found meaningful. I also thank my committee members, Drs. Stephanie Miller and Nicolaas Prins, who provided useful questions and suggestions along the way to actualize this project.

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CHAPTER 1

INTRODUCTION

While research on autism stigma is not a new endeavor, there is a paucity of research examining stigma within the lay population. Negative perceptions about autism spectrum disorder (ASD), such as stigma and social distancing, negatively impact individuals with autism and their families. These negative beliefs can reduce help-seeking behavior in the families of children, such as decreased likelihood that the person will seek out behavioral therapies. Other factors, including socioeconomic status, familiarity, and knowledge about ASD could also play a role, ameliorating or exacerbating, ASD stigma. A better understanding of factors related to stigma within the lay community could allow for education initiatives that demystify misconceptions about people with ASD and aim to increase help-seeking.

Autism Spectrum Disorder

According to the International Classification of Diseases and Related Health Problems – 10th Edition (ICD-10), autism spectrum disorder is a form of developmental disability characterized by impairments in social communication and the presence of restrictive, repetitive patterns of behavior, which are often referred to as stereotypy (World Health Organization, 1993). In 2013, ASD was reclassified to conglomerate the high and low functioning disorders that are now encompassed by ‘the spectrum.’ Classic autism is considered the lower end of the spectrum and is characterized by cognitive and speech difficulties, while high functioning ASD lacks the cognitive and speech difficulties. However, it is important to consider that every individual with autism will present with a different behavioral repertoire and demeanor

Autism spectrum disorder falls under the Pervasive Developmental Disorder umbrella of diagnostic categories as outlined in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, DSM-5 (American Psychiatric Association, 2013). Current diagnostic criteria for autism spectrum disorder can be found in Table 1. Criteria A through D are considered required for diagnosis, while E is not.

Table 1: Current DSM-5 Diagnostic Criteria for Autism Spectrum Disorder

| |
|---|
| A. Persistent deficits in Social Communication and Social Interaction across multiple contexts. |
| B. Restrictive, repetitive pattern of behavior, interests, or activities. |
| C. Symptoms must be present in the early developmental period (may be masked by learned strategies in later life). |
| D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. |
| E. These disturbances are not explained by intellectual disability or global developmental delay. |

In recent years, the rate of autism has increased drastically in the United States. In 2000, the rate of Autism in the U.S. was 1 in 150 children. As of 2014, the rate of a child being diagnosed with an autism spectrum disorder (ASD) has increased to 1 in 59 children (Baio et al., 2014). It is unclear whether this increase in diagnosis is a result of increased occurrence or if it is caused by increased discovery due to awareness (Grinker, 2007). Because of the nature and wide variability within the spectrum, diagnostics are somewhat difficult. Although biological diagnostics are getting closer to fruition, there is currently no biological test to determine if a person is living with ASD. Therefore, in order to assess the disorder, researchers and clinicians must rely on behavioral tendencies of individuals to determine the presence or absence of ASD.

Regarding ASD demographics, White males have appeared to have the highest rates. In 2009, the rate of someone having a documented ASD diagnosis was lower in individuals who

self-identified as Black, Hispanic, or “other” compared to those who identified as White or Asian (Mandell, Wiggins, Carpenter, Daniels, DiGuseppi, Durkin, ... Kirby, 2009). This study also confirmed prior findings that males were more likely to have a diagnosis of an ASD than females. Additionally, children with low (i.e. below 70) or undocumented IQ scores were more likely to have a documented ASD diagnosis. Lastly, children of educated mothers (i.e. mothers with at least some college education) were more likely to have a documented ASD diagnosis than mothers without their high school diplomas (Mandell et al., 2009). It is unclear, however, whether the differential rates of diagnosis reflect actual differences in ASD or other factors, such as elevated stigma and reduced help-seeking, which are well-known for contributing to other health and mental health disparities.

Removing barriers to diagnosis is essential for early intervention. The best outcomes for ASD are achieved with early diagnosis and treatment. For example, integrating children back into the general education classroom has been linked to long-term social gains (Boutot & Bryant, 2005; Fenske, Zalenski, Krantz, & McClannahan, 1985). In fact, Boutot and Bryant (2005) found that students with developmental disabilities were just as likely to be invited to attend a birthday party, play outside, or work on schoolwork within the inclusive classroom, which had not previously been considered the case (Sabornie & Kauffman, 1985; Sabornie, Marshall, & Ellis, 1990). It stands to reason that early detection, which leads to better treatment outcomes, is beneficial for a child’s social integration with their neurotypical peers. However, one myth that often arises is the fact that individuals with ASD cannot benefit from treatment at older ages. If a person finds out their child has autism at the age of 16, treatment may still produce gains.

Help-Seeking

When looking at ASD and all the mystique that it possesses in the lay and medical communities, negative beliefs and perceptions can lead to reduced help-seeking by those who need mental health services (Komiya, Good, & Sherrod, 2000). The primary concern when looking at the effects of autism stigma is that if help is not actively sought, the child will miss an opportunity for treatment during critical developmental periods for milestones such as speech. With no or late-onset treatment, individuals with autism could be at a disadvantage regarding behavioral and educational gains. For example, individuals and healthcare providers in suburban and rural areas are less likely to catch the signs of autism early. This can result in delayed help-seeking and a later age of diagnosis compared to their urban peers (Chen, Liu, Su, Huang, & Lin, 2008).

Generally speaking, somewhere around 70% of individuals who live with mental illness receive no treatment from mental healthcare or general healthcare providers (Deane, Wilson, & Ciarrochi, 2001). Adolescents are at an even greater risk because they are dependent on their parents/caregivers to seek help on their behalf. However, the Theory of Planned Behavior suggests that individuals who have the intention to seek help are more likely to perform actual help-seeking behaviors (Ajzen, 2002). Some individuals seek help through their general practitioners; however, it has been found that mental health stigma is also a problem within medical professionals (Wallace, 2010). Health practitioners themselves, may stigmatize mental health concerns, thus discouraging future help-seeking behavior. Not only do some individuals face these negative beliefs in the lay population and medical professionals, but they also deal with it at home with their families and at school with their peers and teachers. Around 46% of U.S. adolescents with mental health problems stated that their families expressed negative

perceptions by avoiding, pitying, distrusting, or gossiping about them at home (Moses, 2010). In regard to the school setting, 62% of U.S. adolescents with mental health concerns reported that they experienced these negative beliefs in their friend groups by losing friendships and feeling like an outsider because of social isolation and distancing. This finding also indicated that 35% of these adolescents felt stigmatized by their teachers and other personnel at the school by avoiding, fearing, disliking, or thinking them incapable of a task (Connolly, Geller, Marton, & Kutcher, 1992; Moses, 2010). Understanding contributing factors to this barrier to treatment may help inform education and practice efforts to increase relevance and usefulness.

Stigma

For individuals who need mental health services, stigma is a very real and very important concern with negative consequences. Mental health stigma negatively affects employment, healthcare costs, and income level (Sharac, McCrone, Clement, Thornicroft, 2010). In a general sense, there are many issues someone who seeks mental healthcare services may face. In many cases, they face a two-front battle with their area(s) of difficulty. Not only do they face the difficulty itself (i.e. the ASD diagnosis), but they must also deal with the stereotypes, prejudices, and discrimination of individuals in the lay community, which can impact how they think of themselves or their loved ones. Stigma refers to the devaluation and dishonor associated with some attribute. Those who have that attribute often feel subjected to harsh negative criticism or judgments for possessing that attribute (Goffman, 1963). While there is stigma of the self, public stigma is characterized by the negative beliefs about the stigmatized people (stereotypes), such as dangerousness or aggressiveness. These beliefs determine how much the person experiences an emotional reaction towards or agrees with that belief (prejudice), such as fear. Stigma may lead to social distancing and discrimination, such as withholding a resource or avoiding contact with

those individuals (Corrigan & Watson, 2002). This discrimination is influenced by factors such as gender, symptomatology, the type of mental health concern, and the person's knowledge of that particular mental health concern (Phelan & Basow, 2007). Families of children with disabilities experience discriminative stigma as well. Stigma may be greater for individuals with ASD because they often blend in with their neurotypical peers (i.e. children with no known autism spectrum disorder) compared to children with visible disabilities.

Parents often experience considerable stigma due to the socially inappropriate behavior of the child with ASD (Gray, 2002). Mothers have been reported to experience more stigmatization by peers than fathers due to the traditional role of the mother being the primary caretaker. In fact, autism was at one time, thought to be caused by a cold and rejecting mother. Some other folk beliefs include ideas that ASD is caused by God or some other supreme being for wrongdoings or that ASD is the result of a curse or "evil eye" upon the family. While most families with children affected by ASD experience these negative perceptions, some parents choose to ignore outside opinions, others may avoid public places, and refuse advice on how to raise their child.

In terms of familial stigma in relation to the etiology of ASD, parents who report that their child's autism is caused by early childhood traumatic experiences rely less on behavioral treatments, communication training, and assistive devices (Dardennes et al., 2011). While there has been a lot of controversy over whether vaccines cause autism in recent years, there is no evidence that supports this claim (Offit & Gerber, 2009). In a recent study in Canada, around 40% of parents with vaccinated children with autism attributed the cause of their child's autism to routine vaccinations (Mercer et al., 2006). Therefore, even in the face of evidence, some

aspects and facets of stigma continue to be pervasive not only in the lay community, but also in communities with closer proximity to those living with ASD such as their families.

Social Distancing

Social distancing is an aspect of stigma and a common historic way of measuring stigma in research (Link, Yang, Phelan, & Collins, 2004). Social distance is defined as the extent to which someone is willing to be socially intimate with someone from the studied group (e.g., race, social class, someone with mental health concerns, or medical illnesses). People often overestimate the likelihood of violence in individuals with mental health disorders (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999). This is also true of individuals with ASD. This false belief can have potentially harmful effects, such as increased social distance from individuals who suffer from mental health disorders. To avoid this stigma, individuals who need mental health services will often not seek help in order to avoid being labeled as “mentally ill” or deviant. This stigma has been associated with decreased help-seeking to avoid the loss of intimacy with loved ones and friends. In fact, less than 30% of individuals living with a psychiatric disorder seek mental health services in the United States (Regier et al., 1993).

Given the importance of social distancing and stigma as contributing factors to the lack of help-seeking for mental health concerns, it is important to understand factors that contribute to ASD stigma and social distancing among lay people (Corrigan, 2004). Research has pointed to three main areas of additional exploration: knowledge of ASD, familiarity with ASD, and demographic factors.

Knowledge

Formal knowledge is an important aspect of predicting a person’s level of stigma towards mental health concerns. Increases in knowledge have been found to increase a person’s positive

attitudes toward mental health in general (Milin et al., 2016). Research has found that intervention on the level of knowledge can increase the amount of help-seeking a person intends to perform in some domains of mental health (Han et al., 2006). This type of intervention is an easy and efficient method of addressing stigma in the Southern United States due to the dearth of mental health resources in the area.

Considering all of the factors related to stigma, it is surprising that more research does not focus on the factors that are linked to ASD stigma. As of 2016, a large number of limitations were discovered within research regarding autism stigma. A literature review of the measures used in autism stigma research led to findings that suggest that current measures have subpar psychometric properties, lacked autism knowledge subscales, and had little cross-cultural utility (Harrison et al., 2017b). Harrison et al. (2017a) used the literature review to assemble a questionnaire from the pre-existing measures on autism stigma. This measure has been named the Autism Stigma and Knowledge Questionnaire (ASK-Q). This was the first step in creating a measure of autism knowledge and stigma that included subscales that measure etiology, treatment, symptoms, and stigma separately. Research using this scale can help us better understand stigma and identify areas to focus interventions.

Familiarity with ASD

Beyond formal knowledge, research supports that people who are more familiar with individuals with mental illness are less likely to endorse stereotypes of that particular disorder (Corrigan et al., 2001a; Corrigan et al., 2001b; Holmes et al., 1999). Family members, teachers, school counselors that have opportunities to observe or interact with an individual with ASD would, based on such exposures, develop some level of understanding and expectations for ASD-typical behaviors. Familiarity with a person or persons with mental health concerns could result

in increased comfort over time and lead to less social distancing, increased knowledge, and decreased stigma (Corrigan, Green, Lundin, Kubiak, & Penn, 2001b).

Demographic Factors

Some of demographic factors that have been repeatedly related to increased stigma are sex, age, and socioeconomic status. Young age has been associated with higher levels of stigmatized beliefs regarding mental health (Anglin et al., 2006). Males are more likely to prefer greater social distance from children with mental illnesses (e.g., depression and ADHD) and their families than their female counterparts (Martin et al. 2007). Additionally, it has been shown that mothers rate children more positively than fathers in the same dyad (Rosenbaum et al., 1987).

Individuals with higher levels of education have been found less likely to prefer social distance from both the child and the child's family (Mukolo and Heflinger, 2011). Contrary to the expected, income level does not trend with level of education. Even though education level is negatively related to social distance preferences, higher income levels are associated with greater social distancing. Additionally, higher income level was associated with beliefs that individuals with mental health concerns should be punished for aggressive and violent behavior (Anglin et al. 2006; Parcesepe & Cabassa, 2013). Individuals with high levels of education did not have this same belief regarding the use of punishment for aggressive behavior.

Present Study

This study aimed to investigate the relationship between demographic variables, stigma, social distancing, and help-seeking behavior within the lay community of the Southern United States. The Southern U.S. may have particularly low rates of mental health knowledge and help-seeking. This could be related to lower education and income levels, decreased access to care in

more rural areas, negative perceptions, and stigma. The Southern U.S. is also more religious and individuals may harbor religious or spiritual beliefs that inhibit help-seeking.

Because the rates of autism are rising among the overall population, it is increasingly important to study what prevents people with autism and their families from seeking early interventions. Even though behavioral treatments for autism, such as applied behavior analysis, have been proven to be effective, there are still gaps in treatment seeking due to income, education level, negative beliefs, and stigma. When a person faces higher levels of stigma, they are less likely to seek help, such as diagnostic or therapeutic services in a timely manner (Evans-Lacko, Brohan, Mojtabai, Thornicroft, 2012). Social distance is another component of stigma and may also be associated with reduced help-seeking and poorer overall outcomes. Previous studies have found that sex, age, education level, and socioeconomic status contribute to a person's level of stigma toward mental illness; however, there has been conflicting research about racial background (Anglin et al., 2006; Corrigan and Watson, 2007; Martin et al., 2007).

Although some research has been conducted on lay stigma, the research specific to autism stigma is elusive and methodologically lacking. The use of the new measure by Harrison et al. (2017a) contributes to the small pool of research done on populations outside the family of individuals with autism. In the present study, demographic factors are considered first to examine their relationship to ASD knowledge, stigma, and help-seeking behavior. Next, the roles of familiarity and formal ASD knowledge will be explored to ascertain its contribution to stigma and help-seeking. Finally, the extent to which stigma and social distancing predict help-seeking intentions will be examined.

The following hypotheses were proposed: 1) Demographics (gender, age, income and education) along with familiarity and knowledge will predict autism stigma. Specifically,

individuals of higher income, lower education, male gender, lower levels of autism knowledge, and decreased familiarity with someone with autism will have increased levels of autism stigma.

Knowledge, followed by familiarity will contribute more variance in stigma than demographics.

2). Demographics along with familiarity and knowledge will predict social distancing.

Specifically, individuals of higher income, lower education, male gender, lower levels of autism knowledge, and decreased familiarity with someone with autism will have increased levels of social distancing. Again, knowledge and familiarity will contribute more variance in stigma than demographics 3) individuals who have higher levels of stigma and social distancing are less likely to seek help for a loved one with autism-like symptoms.

CHAPTER 2

METHODS

Participants

Participants were purposefully sampled to include individuals specifically within the Southern U.S. All participants were from the state of Mississippi. To ensure a diverse sample, recruitment was performed through targeted community groups, such as churches, school staff, and medical clinic waiting rooms. Most participants completed the questionnaire via pen and paper, but some chose to complete the survey using a Qualtrics link on their personal devices. Participants (N=108) were primarily female (77.8%) with an average age of 42 (SD = 12.69). The following information describes the participants' ethnic composition: White (N = 86; 79.6%), African American/Black (N = 20; 18.5%), Asian/Asian American (N = 1; 0.9%), Native American (N = 1, 0.9%), and Multiracial (N = 1; 0.9%). The mean reported household income was between \$40,000 and \$50,000. Just over half of the sample had at least an associate's degree (54.6%) while 18.5% reported never attending college or vocational training. Participants were 100% Christian with only two respondents indicating a non-protestant affiliation.

Procedures

The study was approved by the institutional review board at the university where the study was conducted. Data was collected and organized through a mid-sized university in the Southern United States. Everyone who participated was placed in a drawing for one of ten \$20 Amazon or Walmart gift cards. The sample was collected using mobile devices (e.g. phones and tablets) as well as through the use of pen and paper where internet service and/or smart phones

were not available. The questionnaire began with a brief explanation of the study, what was required to participate, incentives provided, and the opportunity to consent to the research study. After participants completed the questionnaire, they were given information about ASD from the National Institute of Mental Health (NIMH).

Measures

The questionnaire included the following measures: a basic demographic questionnaire, the adapted Level of Familiarity Scale for autism, the Autism Stigma and Knowledge Questionnaire (ASK-Q), the Autism Social Distance Scale (SDS), and the General Help-Seeking Questionnaire – Vignette Version (GHSQ-V).

Demographics Questionnaire. A basic demographics questionnaire was administered to collect data on socioeconomic status, age, gender, education level, and ethnic background.

Level of Familiarity Scale for Autism. The Level of Familiarity Scale (LOF) for Autism was originally developed to look at endorsement of stereotypes for individuals with serious mental illness. This will be adapted to specify the “mental illness” as autism spectrum disorder. Participants will read a total of 11 items that vary in how familiar the participant is with individuals on the autism spectrum. This measure was taken from “A Toolkit for Evaluating Programs Meant to Erase the Stigma of Mental Illness” by Patrick Corrigan (2012).

This is a well-used measure that has psychometric support in determining how intimately someone knows an individual with the mental illness in question (i.e. autism spectrum disorder in the current study). The participant checks the statement that represents their experience with a person with autism. The questions vary from “I have never observed a person that I was aware had an autism spectrum disorder” to “I have an autism spectrum disorder.” The scores range

from 11 (most intimate contact) to 1 (little intimacy). If the participant endorses more than one statement, the score considered the highest level of intimacy endorsed will be the assigned score.

According to the National Assessment of Adult Literacy, Mississippi's average rate of illiteracy at a Basic level is around 16% with rates reaching 30% in rural and impoverished counties (National Center for Education Statistics, 2003). Because this limitation will likely appear in the sample to be collected, the grade level of this measure was calculated. Using the Flesch-Kincaid readability test, the grade level was determined to be at the 7th grade level, which means that the average 12-year-old should be able to read and understand the measure.

Autism Stigma and Knowledge Questionnaire. The Autism Stigma and Knowledge Questionnaire was developed by Harrison et al. (2017a) as a methodology of looking at autism stigma in populations outside of the measures that have been developed for isolated and specific groups of people, such as mothers of children with autism and healthcare professionals. These older, more specific measures have been criticized for their limitations in cross-cultural utility, exclusion of clear knowledge subscales, and subpar psychometric properties (Harrison et al., 2017b). Participants will read 49 statements that compose 4 different subscales. Participants then are asked whether they agree or disagree with the statement.

The knowledge subscales measure specific knowledge regarding Diagnosis/Symptomatology (D/S), Etiology (ET), Treatment (TR), and Stigma (ST). Questions in the Diagnosis/Symptomatology subscale assess knowledge regarding the diagnosis and common symptoms associated with an autism spectrum disorder diagnosis. Items within the Diagnosis/Symptomatology subscale include statements such as "Some children with autism may lose acquired speech" and "Most children with autism may not look at things when you point to them." Items in the Etiology subscale assess knowledge regarding the cause(s) and

classifications of autism. These items include statements such as “Vaccinations cause autism” and “Autism is a brain-based disorder.” Treatment subscale items assess the knowledge of possible treatments. These statements include the following: “Medication can alleviate the core symptoms of autism” and “The earlier treatment of autism starts, the more effective it tends to be.” The Stigma subscale is the last of the subscales and measures the endorsement of stigma related to the diagnosis, etiology, and treatment outcomes of individuals with autism. The Stigma items include statements such as “Autism is caused by God or a supreme being” and “Autism is caused by cold, rejecting parents.” The overall scores range from 0 to 48 due to the first item acting as a screener for personal experience with an individual on the autism spectrum.

Once again, the grade level of this measure was calculated. Using the Flesch-Kincaid readability test, the grade level of the measure was determined to be between 7th and 8th grade, which means that an average 12-year-old would be able to read and understand the measure.

Psychometrics for this measure were calculated using diagnostic classification model (DCM-based classification) analyses. The resulting test-retest reliability coefficients are as follows: 0.982, 0.954, 0.984, and 0.933 for the four subscale classifications of the measure. To ensure the strong psychometric properties, Harrison et al. (2017a) calculated the internal consistency and found Cronbach’s Alpha to be 0.88, which is considered high consistency.

Items that did not hang well within each subscale were removed. Items in the Stigma subscale that measured knowledge of stigma—instead of assessing stigma itself—were also removed to make the Stigma subscale more of a measure of the participant’s stigma. The psychometric properties of the measure have only preliminary support, but the current study aims to help provide support for the pre-existing positive psychometrics. A limitation of the use of the ASK-Q is the use of the measure on a continuous basis instead of using the categorical

classifications established by the DCM analyses. This is why the measure of social distance is being used alongside it because it is a long standing measure of stigma that has excellent psychometric properties (i.e. Autism Social Distance Scale).

Autism Social Distance Scale. The Autism Social Distance Scale has been adapted by Gillespie-Lynch et al. (2015) from the longstanding, psychometrically sound measure of stigma, the Social Distance Scale (Bogardus, 1933). Bogardus originally used the measure to examine social distance from non-clinical outgroups, such as racial minorities. Participants are instructed to read 6 questions and rate how likely they would be to do certain things with individuals with autism. The questions include things like “How willing would you be to move next door to someone with autism?” and “How willing would you be to marry or date a person with autism?” The Likert-type scale responses range from 1 (definitely willing) to 4 (definitely unwilling). Therefore, scores can range from 6 to 24 with higher scores signifying greater social distance, hence greater stigma as well.

The grade level for this measure using the Flesch-Kincaid readability test indicated that the measure is on a 5th grade reading level. Therefore, the measure would be appropriate for the average 10-year-old.

General Help-Seeking Questionnaire – Vignette Version. The General Help-Seeking Questionnaire – Vignette Version (GHSQ-V) is a well-established and validated measure that has been used to measure help-seeking intention for many years (Wilson, Deane, Ciarrochi, & Rickwood, 2002). As mentioned by Ajzen (2002), intentional behavior is predictive of future behavior occurrence. The questionnaire provides the participant with a case vignette of an individual who is presenting with diagnostic criteria for Autism Spectrum Disorder. They are then asked to rate how likely they would be to seek help if they or their child were experiencing

the same difficulties as the person in the vignette. The following are some of the individuals assessed as sources of help within the GHSQ-V: intimate partner, parents, friends, mental health professionals, doctors, and religious leaders. This vignette was adapted from a pre-existing vignette created by the mobile medical reference with their permission. Participants are then asked what, if anything, they perceive to be wrong with the character in the vignette and whether or not the character should seek help.

Analytic Strategy

The data set was analyzed with a series of multiple regressions. The first regression used demographics, knowledge, and level of familiarity as predictors of stigma (Figure 1). The next multiple regression explored the predictive abilities of socioeconomic status, knowledge, and familiarity on social distancing (Figure 2). Lastly, a multiple regression was conducted to analyze the predictive qualities of stigma, social distancing, and any significant predictors from previous analyses, such as demographics, knowledge, and familiarity (Figure 3). This was used to predict help-seeking intentions/beliefs.

CHAPTER 3

RESULTS

Prior to completing any statistical analyses, the data set was cleaned by excluding individuals who were not from the state of Mississippi and who did not complete over 5% of any of the variables. Descriptive statistics were calculated and the mean response was used to replace any missing data in order to calculate and exclude multivariate outliers and address any non-standardization difficulties. The data set was analyzed for outliers using Mahalanobis distance. Outliers ± 3.3 standard deviations from the mean were excluded from the analysis. Overall, results partially supported the hypotheses, with some exceptions. First, descriptive data is presented, followed by results for each regression.

Descriptive Statistics

Before performing the regressions, descriptive statistics were calculated and analyzed. The means scores and standard deviations for the variables of interest can be found in Table 2. Overall, the sample of individuals was knowledgeable about ASD. Scores on the Knowledge subscale ranged from 27 to 47 with a mean score of 39.76. The mean response of the Knowledge subscale was within the “adequate knowledge” descriptor of the ASK-Q.

Scores on the LOF-A ranged from 2 to 10 with a mean response of 7.10. The mean response on the level of familiarity scale was determined to be in the “medium intimacy” range as described by Corrigan (2012). Scores on the ASDS ranged from 6 to 24, which is the range of the measure, with a mean response of 9.95. This mean response indicates a mild preference of social distance from individuals with ASD.

Lastly, scores on the GHSQ-V ranged from 26 to 104 with a summation mean response of 77.04. The mean response on individual items was 4.23 which equates to a score between “likely” and “unlikely” on the scale. The mean score on individual items of the adult version of the GHSQ-V was 3.61 which equates to “unlikely” on the scale. Respondents rated their intimate partner highest when seeking help as an adult. The mean score on individual items of the child version of the GHSQ-V was 4.11 which is between “likely” and “unlikely” on the scale. Participants rated their intimate partner and their doctors highest when seeking help for their child.

Table 2
Descriptive Statistics

| | Full Sample | | Females | | Males | |
|------------------------|-------------|-------|---------|-------|-------|-------|
| | Mean | SD | Mean | SD | Mean | SD |
| Social Distance (ASDS) | 9.95 | 3.79 | 9.68 | 3.86 | 10.92 | 3.46 |
| Stigma (ASK-Q) | 1.15 | 1.39 | 1.04 | 1.31 | 1.54 | 1.61 |
| Knowledge (ASK-Q) | 39.76 | 4.35 | 40.34 | 4.13 | 37.75 | 4.60 |
| Familiarity (LOF-A) | 7.10 | 2.10 | 7.18 | 1.98 | 6.83 | 2.50 |
| Help-Seeking (GHSQ-V) | 77.04 | 15.65 | 77.51 | 16.86 | 75.38 | 10.50 |
| Age | 42.27 | 2.10 | 42.01 | 1.98 | 43.17 | 2.50 |
| N | 108 | | 84 | | 24 | |

Hypothesis 1

Hypothesis 1 stated that demographics, familiarity, and knowledge would predict stigma as measured by the ASK-Q Stigma subscale. A hierarchical multiple regression was used to test this hypothesis. Overall, the model predicted 41.5% of the variance ($R^2=.415$, $F(6,100) = 11.808$, $p < .001$). The only significant predictor within the model (Figure 1) was overall knowledge measured by the ASK-Q etiology, treatment, and diagnosis subscales ($\beta = -.664$, $p < .001$).

Hypothesis 2

Hypothesis 2 indicated that demographics, familiarity, and knowledge would predict social distancing as measured by the ASDS. An additional multiple regression was used to test this hypothesis. This model (Figure 2) predicted 21.5% of the variance ($R^2=.215$, $F(6,100) = 4.561$, $p < .001$). The only significant predictor was overall familiarity with individuals with autism ($\beta = -.244$, $p < .05$).

Hypothesis 3

Hypothesis 3 stated that demographics, familiarity, knowledge, stigma, and social distancing would predict a person's help-seeking intentions. The last multiple regression was performed to explore if the aforementioned demographic variables, familiarity, overall knowledge of ASD, and the two types of stigma (i.e., social distancing and knowledge misconceptions measured by the stigma subscale of the ASK-Q) predicted a person's willingness to engage in help-seeking behavior. The measure of help-seeking was the total of the General Help-Seeking Questionnaire – Vignette Version (GHSQ-V). Overall, this model (Figure 3) predicted 22.5% of the variance ($R^2=.225$, $F(8,59) = 2.137$, $p < .05$). The only significant predictor for help-seeking intentions was social distancing ($\beta = -.430$, $p < .05$). Correlations of all the variables associated with this, and previous regressions, are displayed in Table 3.

Exploratory post-hoc analyses

Because the knowledge score is composed of three different subscales, an exploratory analysis was performed to see what portions of the knowledge scale were correlated with the variables of interest (i.e., social distance and help-seeking intentions). It was found that social distancing is negatively correlated with the treatment, $r(102) = -.35$, $p < .001$, and etiology, $r(102) = -.22$, $p < .05$, subscales of the ASK-Q. Additionally, the correlation between the treatment

subscale of the ASK-Q and help-seeking behavior for children was positive and significant, $r(102) = .27, p < .01$.

Table 3

Correlations

| | Help- Seeking | Age | Gender | Education | Income | Familiarity | Stigma | Knowledge | Social Distancing |
|----------------------|------------------|-------|--------|-----------|--------|-------------|--------|-----------|----------------------|
| Help- Seeking | - | | | | | | | | |
| Age | -.062 | - | | | | | | | |
| Gender | -.044 | .043 | - | | | | | | |
| Education | .012 | -.030 | .192 | - | | | | | |
| Income | -.012 | .032 | .127 | .522 | - | | | | |
| Familiarity | .159 | -.062 | -.028 | .197 | .255 | - | | | |
| Stigma | -.214 | .042 | .136 | -.069 | -.092 | -.101 | - | | |
| Knowledge | .185 | -.128 | -.165 | .164 | .108 | .034 | -.701 | - | |
| Social Distancing | -.426 | .224 | .007 | -.151 | -.270 | -.215 | .253 | -.220 | - |

Table 4
Regressions

| | | B | β | T | R² | Δ R² |
|--------------------------|-------------|----------|----------|-----------|----------------------|------------------------|
| Stigma | | | | | | |
| Step 1 | | | | | .036 | .036 |
| | Age | .005 | .044 | .958 | | |
| | Gender | .526 | .158 | .451 | | |
| | Education | -.033 | -.044 | 1.617 | | |
| | Income | -.046 | -.078 | -.402 | | |
| Step 2 | | | | | .049 | .013 |
| | Age | .004 | .035 | .351 | | |
| | Gender | .496 | .149 | 1.524 | | |
| | Education | -.016 | -.022 | -.197 | | |
| | Income | -.044 | -.074 | -.684 | | |
| | Familiarity | -.077 | -.116 | -1.158 | | |
| Step 3 | | | | | .415 | .366 |
| | Age | .001 | .011 | .141 | | |
| | Gender | -.043 | -.013 | -.164 | | |
| | Education | .132 | .174 | 1.919 | | |
| | Income | -.041 | -.069 | -.806 | | |
| | Familiarity | -.043 | -.065 | -.817 | | |
| | Knowledge | -.213 | -.664 | -7.906*** | | |
| Social Distancing | | | | | | |
| Step 1 | | | | | .133 | .133 |
| | Age | .060 | .199 | 2.131* | | |
| | Gender | 1.411 | .157 | 1.691 | | |
| | Education | -.238 | -.116 | -1.122 | | |
| | Income | -.304 | -.191 | -1.843 | | |
| Step 2 | | | | | .195 | .062 |
| | Age | .054 | .178 | 1.955 | | |
| | Gender | 1.233 | .137 | 1.521 | | |
| | Education | -.138 | -.067 | -.660 | | |
| | Income | -.292 | -.183 | -1.829 | | |
| | Familiarity | -.463 | -.256 | -2.783** | | |
| Step 3 | | | | | .215 | .020 |
| | Age | .052 | .172 | 1.907 | | |
| | Gender | .889 | .099 | 1.068 | | |
| | Education | -.043 | -.021 | -.201 | | |
| | Income | -.290 | -.182 | -1.831 | | |
| | Familiarity | -.441 | -.244 | -2.664** | | |
| | Knowledge | -.135 | -.157 | -1.608 | | |

Table 4 (cont.)
Help-Seeking

| | | | | | | |
|------------|-------------|---------|-------|----------|------|------|
| Step 1 | | | | | .006 | .006 |
| | Age | -.084 | -.059 | -.468 | | |
| | Gender | -1.760 | -.044 | -.346 | | |
| | Education | .255 | 1.292 | .029 | | |
| | Income | -.138 | -.020 | -.133 | | |
| Step 2 | | | | | .225 | .218 |
| | Age | .081 | .057 | .476 | | |
| | Gender | .033 | .001 | .007 | | |
| | Education | .020 | .002 | .017 | | |
| | Income | -1.197 | -.171 | -1.215 | | |
| | Familiarity | .877 | .103 | .852 | | |
| | Stigma | -.712 | -.068 | -.412 | | |
| | Knowledge | .244 | .065 | .388 | | |
| | Social | -1.779 | -.430 | -3.380** | | |
| | Distancing | | | | | |
| *** p<.001 | | **p<.01 | | *p<.05 | | |

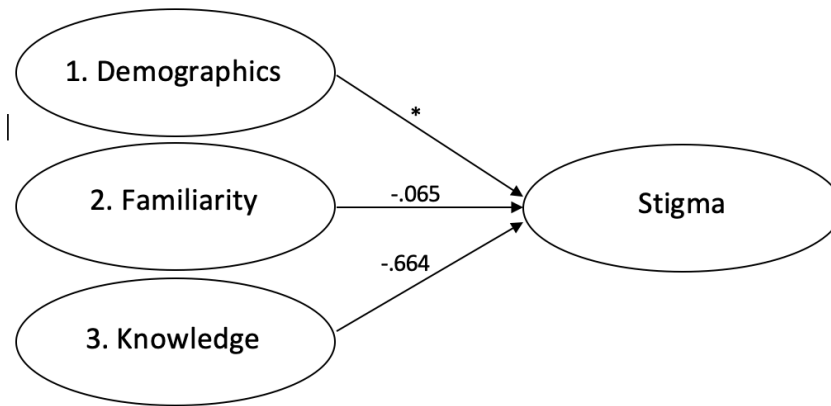


Figure 1. The predictive effects of demographics, familiarity, and knowledge for stigma (H1).
 *Demographic standardized coefficients can be found in Table 1.

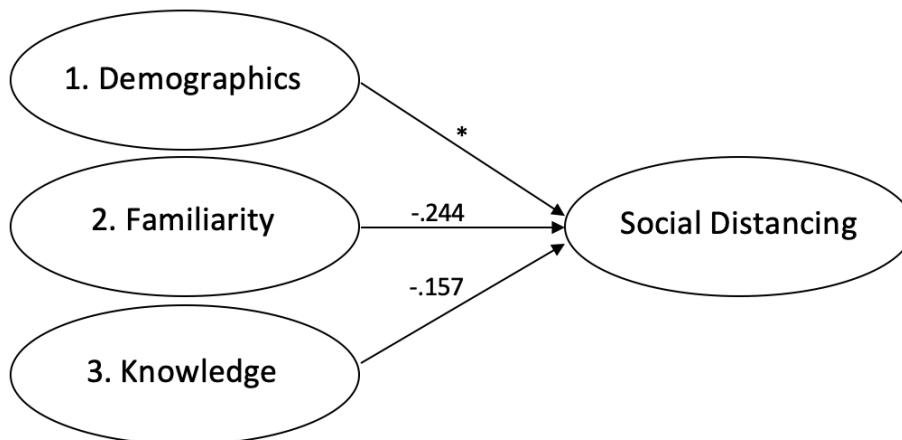


Figure 2. The predictive effects of demographics, familiarity, and knowledge for social distancing (H2).
 *Demographic standardized coefficients can be found in Table 1.

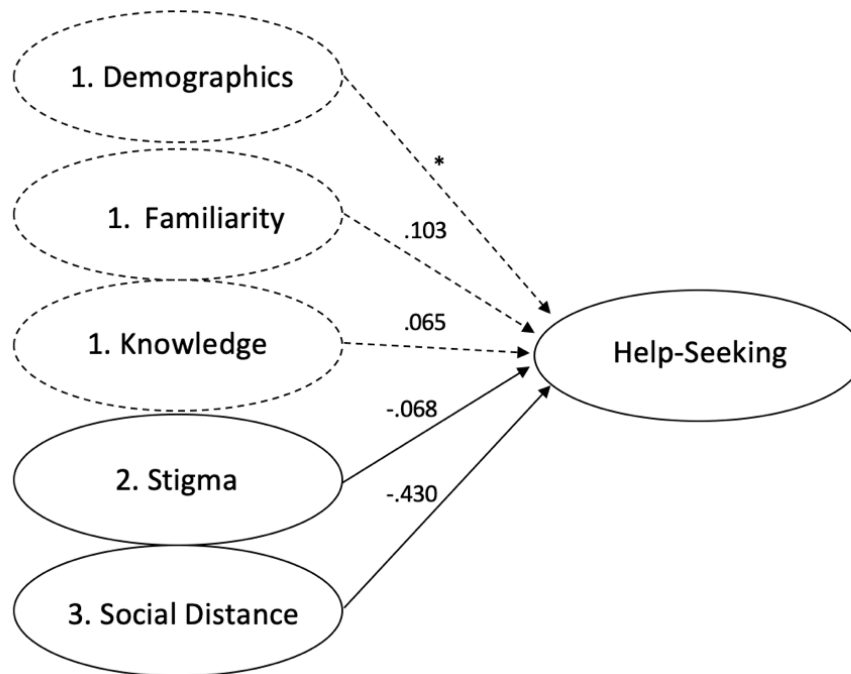


Figure 3. The predictive effects of demographics, familiarity, knowledge, stigma, and social distancing for help-seeking intentions (H3).

*Demographic standardized coefficients can be found in Table 1.

CHAPTER 4

DISCUSSION

It is critically important to acknowledge and understand the development and maintenance of stigma in the general populace. With this knowledge, scientists and practitioners can better understand their communities and positively impact the stigma and help-seeking behavior of the local general public. The current study investigated the ability of certain variables (i.e., demographics, familiarity, and knowledge) to predict stigma and social distancing. In addition, the study explored the relationship of those factors (i.e., demographics, familiarity, knowledge, along with stigma and social distancing) with help-seeking intentions. Overall, the hypotheses were partially supported, affirming the importance of knowledge and familiarity with ASD. Below, the results of the main hypotheses are discussed individually followed by limitations, implications, and future directions.

Do Demographics, Familiarity, and Knowledge Predict Stigma?

Contrary to other fields of stigma research in mental health, age, gender, income, and education level were not associated with higher levels of stigma; nor was familiarity associated with stigma. Demographics may play a lesser role in ASD than other factors. Indeed, results indicated that overall knowledge of Autism Spectrum Disorder (ASD) is the only significant predictor of stigma. This stigma is associated with common misconceptions held about the etiology, diagnosis, and treatment of ASD (e.g., autism is caused by cold, rejecting parents and everyone with autism is aggressive). Therefore, these results are expected. The more knowledge

a person possesses, the less likely a person is to make assumptions that result in one of the many misconceptions held about individuals with ASD or their relatives.

This measure of stigma, however, is taken from the same measure used to assess a person's knowledge about the diagnosis, treatment, and etiology of ASD. These results, therefore, should be interpreted with caution. For that reason, social distancing was also used as a means of measuring stigma and, more specifically, discriminatory behavior.

Do Demographics, Familiarity, and Knowledge Predict Social Distancing?

Once again, contrary to previous research done in mental healthcare, age, gender, income, and education level were not associated with higher levels of social distance. It was found, however, that the more familiar a person is with ASD, the less likely they are to socially distance themselves from people with autism. Previous research also corroborates these findings. Corrigan et al. (2001b) suggests that the exposure to become more familiar with an individual with a mental health concern could make the person more comfortable around similar people. This comfort, in turn, can decrease the amount of social distance a person deems necessary between themselves and the "other". The more a person knows about the treatment and etiology of ASD, the less likely they are to endorse greater amounts of social distance. While age was a good predictor of social distance initially, this was not true when familiarity was added into the group. One might think this is due to a relationship between familiarity and age; however, there was little-to-no relationship between these two variables. Perhaps significant variability exists in familiarity with ASD across age groups. Regardless, the correlation between age and social distancing was small.

Do Demographics, Familiarity, Knowledge, Stigma, and Social Distancing Predict Help-Seeking?

Age, gender, income, and education level were not associated with help-seeking intentions. Yet again, the results within the demographics were unexpected. Individuals may feel less stigmatized due to increased insurance coverage for autism-related services and the transdiagnostic need for other adjunctive services commonly required for children with ASD (e.g., occupational therapy and speech therapy). While the amount of knowledge a person has predicted the Stigma subscale of the ASK-Q, the Stigma subscale was not associated with help-seeking intentions. Social distance was, however, the only predictor of help-seeking intentions. The more social distance a person prefers for individuals with ASD, the less likely that person is to seek help if they or a loved one needed ASD-related services. From the aforementioned results, it was observed that familiarity is highly predictive of how much social distance a person prefers. This link is important to remember when designing education and awareness campaigns, as opportunities to increase familiarity via exposure.

Implications

Prior research indicates parents experience the effects of stigma due to their children's socially atypical behavior as well (Gray, 2002). It should, therefore, be within the scientific domain to understand and attenuate any stigma or barriers to help-seeking behavior. The present study suggests that increasing a person's familiarity with autism would decrease the likelihood of a person preferring greater amounts of social distance. This would, in turn, place that individual at a reduced likelihood to avoid seeking psychological help if needed.

Results of the present study have several implications for public education and clinical care. First, interventions should aim to familiarize the community with individuals with ASD.

This could be accomplished through actual exposure to people on the autism spectrum and/or through media campaigns that highlight individuals with ASD that can advocate for themselves and their community. Dissemination of knowledge related to the cause and treatment of autism is important as well, since it was related to stigma. Knowledge about ASD may also be spread through media (e.g., PSAs) and/or embedded into school-based health curricula. This is important, as 13% of our sample endorsed a belief that vaccines cause ASD. Churches may be another important venue for education and familiarization in the South, as Christianity was endorsed by 100% of our sample, 15% said ASD was caused by God, with 5% endorsing the idea that ASD resulted from a curse or evil eye. At the level of clinical care, providers should be aware of such community beliefs and specifically, whether their patients and their families have such beliefs that could impact stigma, social distancing and/or help-seeking.

Limitations and Future Directions

There were some limitations to this study. First, the measure of knowledge and stigma (ASK-Q) is still in its early stages of development and validation; although, initial findings support the use of this measure as a tool in research. The ASK-Q also contains the stigma subscale used in the first analysis of the current study. This is a potential confound and limitation as well considering a component of the measure is used as a predictor and outcome variable within the first analysis. In addition to measurement limitations, a larger sample size with more male participants would likely have benefited gender-based analyses and results in general, but a community sample of men in healthcare settings was difficult to obtain. Likewise, it may be beneficial to use a unidimensional measure of help-seeking to affirm the effects of help-seeking intentions.

A randomized controlled trial (RCT) of such interventions would prove beneficial to see if exposure efforts would provide attitudinal gains for individuals with higher levels of social distancing. Future developments in this line of research should focus on parents of children between the time of birth and around the time of puberty. This would allow researchers to see the variables that might impact the parents' willingness to seek help in a child who might potentially need mental health services. It would also be beneficial to have the parental dyad complete the measures when possible to subsequently increase the amount of male participants.

Future iterations of this research should focus on increasing diversity outside of the rural Southern United States and other regions of the world. For example, ASD occurs in similar and stable rates worldwide including in low and middle income countries; however, ASD research and ASD stigma research is lacking (Elsabbagh et al., 2012). It is also important to expand this research into cultures outside of W.E.I.R.D. (western, educated, industrialized, rich, and democratic) locations. This helps expand this research into the understudied 20% of the world because those places have people who are experiencing similar difficulties as the rest of the world. While the rest of the world is experiencing similar rates of ASD, there are places where the rate of ASD is lower than that observed in the United States. The global rate of autism is suspected to be around 1 in 160 individuals, which is much lower than that currently observed in the United States (Elsabbagh et al., 2012).

Further research within this area is warranted to extricate the tangled relationships of knowledge, familiarity, stigma, help-seeking and other demographic or cultural variables. Researchers should aim to establish programs to increase familiarity with ASD in the average community member. Additional curricula to increase a person's knowledge of ASD would also prove useful to address many of the issues experienced by those who are seeking services related

to the autism spectrum and related disorders. Another important research question would be related to whether who holds these stigmatizing views matters to the help-seeker. It could be that it does not matter, and all that matters is the subjective experience of the help-seeker (e.g., parent, teenager, grandparent, guardian, extended family, etc.). According to Kleinman (1980) the social meanings of disorders, called Explanatory Models (EMs) are central, as they influence the entire help-seeking pathway, from realization of a problem to symptom communication, help-seeking, treatment processes and even outcomes. Kleinman's EM concept, along with his proposed questions, can positively impact a help-seeking family. This model allows the medical professional to work alongside the family using their own language and culture to conceptualize their problem and encourage future help-seeking behavior. Overall, these findings provide a framework for future research and potentially useful starting points for prevention and intervention efforts in the Southern United States.

According to the study's findings, increased familiarity was associated with decreased levels of social distancing. Increased social distancing was, in turn, associated with decreased levels of help-seeking intentions. Early diagnosis and intervention are vital for the long-term prognosis of children with ASD. Overall, while the sample as a whole was considered to have "adequate" knowledge, these results still indicate the increased need for awareness campaigns for autism spectrum disorder.

CHAPTER 5

CONCLUSION

The current study investigated the ability of certain variables (i.e., demographics, familiarity, and knowledge) to predict stigma and social distancing. The study also explored the relationship of those factors (i.e., demographics, familiarity, knowledge, along with stigma and social distancing) with help-seeking intentions. According to the study's findings, increased familiarity was associated with decreased levels of social distancing. This affirms the roles of familiarity and knowledge on social distancing and help-seeking. These factors were better predictors than demographics (i.e., sex, age, income level, and education level). Future intervention efforts should focus on the familiarization, education, and exposure to individuals on the autism spectrum to spread accurate information to the public. Future research should focus on confirming these results as well as including more of the neglected minority populations in lower income and less educated regions of the world.

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- Worked closely with direct support staff to help ensure the behavioral interventions were implemented in a multitude of environments.
- Trained staff using behavior-based curriculum to increase positive/adaptive behaviors.

Co-Leader of Diversity Support Groups (LGBTQIA and International Students)

2016-2017

- Facilitated clinical support group discussion and stress reduction strategies.
- Helped connect group members with various resources and service providers.

Research Experience

Graduate Research Assistant, University of Mississippi; Oxford, MS

2016-Present

- Consulted with team members in need of help with data collection and statistical analyses.
- Organized team members and tasks to efficiently finalize projects that were near completion.
- Assisted in research design and development.

Research Assistant, University of Mississippi; Oxford, MS

2015-2016

- Assisted in research design and development.

- Managed and restructured databases for use in other research ventures, such as work for the Search Institute.
- Organized team members and tasks to efficiently finalize projects that were near completion.

Research Team and Lab Member, University of Mississippi; Oxford, MS 2014-2015

- Entered data and provided analyses of tests performed on environmental conservation attitudes of college students before and after an environmental psychology course.
- Designed research materials for Participatory Research in Tanzania on environmental conservation.

Research Presentations

Johnson, L.R., Drescher, C., Hankton, U., Kihilo, R., Pal, S., **Courson, C.S.**, Scales, Peter. (November, 2018). *From Dar Es Salam to the Delta: Adolescent Developmental Assets*. Poster presented at the fourth convention of the Caribbean Regional Conference of Psychology. Kingston, Jamaica.

Courson, C.S. & Johnson, L. (2018, March). *Nature Experience and Spirituality: The Role of Connectedness*. Poster session presented at the Annual Convention of the Southeast Psychological Association (SEPA). Charleston, South Carolina.

Ho, L.Y., Johnson, L.R., Assenga, S., **Courson, C.S.**, Schulenberg, S.E., & Karim, Z.N. (May, 2016) Measuring Perceived Meaning in Life among Tanzanian Youth and Emerging Adults. Poster Presentation at the Association for Psychological Sciences (APS) Conference. Chicago, IL.

Invited Presentations

Courson, C.S. (2018, October). *Substance Use Disorders*. Guest lecturer in Abnormal Psychology at the University of Mississippi.

Courson, C.S. (2018, October). *Needs-Hierarchy Theory*. Guest lecturer in Personality Psychology at the University of Mississippi.

Courson, C.S. (2019, October). *Operant Learning*. Guest lecturer in Learning and Behavior at the University of Mississippi.

Courson, C.S. (2019, November). *Dimensions and Diagnosis of Autism Spectrum Disorder and the Case of Angela*. Guest lecturer for the clinical psychology department at the University of Mississippi.

Editorial and Service Experience

Poster Session Judge, University of Mississippi Research Conference
April 2018

Assistant Reviewer, Routledge Publisher
February 2017

- Multiple manuscript reviews for the book project *Understanding Student Experience in Higher Education: New Tensions, Issues, and Perspectives*.

Assistant Reviewer, Journal of International Students
April 2017

Assistant Reviewer, Journal of Environmental Psychology
February 2018

Professional Affiliations

- Division 25: Behavior Analysis - Student Member
- Division 35(4): Section for Lesbian, Bisexual, and Transgender Concerns - Student Member
- Division 36: Society for the Psychology of Religion and Spirituality - Student Member
- Division 40: Society for Clinical Neuropsychology - Student Member
- Division 54: Society of Pediatric Psychology - Student Member

References

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